



Bridging the Gap: Communicating with Family and Friends

Sage Bolte, ABD, LCSW, OSW-C

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OPERATOR:

Good afternoon. My name is Raquel, and I will be your conference operator today. At this time, I would like to welcome everyone to the Living Beyond Breast Cancer conference call. . . .

After the speaker's remarks, there will be a question-and-answer session. . . Ms. Elyse Caplan, you may begin your conference.

ELYSE S. CAPLAN, MA:

Thank you, Raquel. Welcome, everyone, to Living Beyond Breast Cancer's teleconference, *Bridging the Gap: Communicating with Family and Friends*.

This is the first time we've offered a teleconference on this subject. . . . We really feel that at this time of year, as the year is coming to an end and the holidays [are] approaching, communication issues may arise for some of you. Today's program will provide discussion of some of the key issues that may affect women diagnosed with breast cancer. Whether you're newly diagnosed, in treatment, have completed treatment, or are years beyond, communication is key to getting your needs met. Our speaker [will discuss] some effective strategies to help you comfortably make your way through . . . a very challenging time.

I'd like to thank everyone who took the time . . . to join us and many other women for today's program. As Raquel said, I am Elyse Caplan. I'm the education director here at Living Beyond Breast Cancer, and I'm happy to serve as the moderator for today's program.

Many of you may have participated in past LBBC teleconferences, but just a reminder that it will be interactive in nature. We will start with the speaker presentation, and following that a question-and-answer session. So, some of the things that you'll hear about today are how to manage changing roles in some of your relationships, communicating with your loved ones and friends, and also addressing some of the barriers to communication that may affect you in

caring for yourself and getting the support you need and deserve.

I'm sure you know that LBBC offers an array of educational programs. Teleconferences are just one way that we can get information out to large groups of people across the country and around the world. . . . Our next teleconference will be our annual update from the San Antonio Breast Cancer Symposium, which many of you may be familiar with. This international symposium of scientists, oncologists and health professionals from across the world convenes each year in December in San Antonio [<http://www.sabcs.org>]. . . . Monday, January 26, 2009, [is set for Living Beyond Breast Cancer's update of the SABCS event] . . . You will soon [receive] . . . details [on the January 26 event] in your snail mail or your e-mail inbox [Read the transcript from the SABCS teleconference at <http://www.lbbc.org/data/transcript-file/LBBCsabcs09.pdf>].

At all other times, of course, if you want to get up-to-date on our publications and other services and programs, please visit our Web site [<http://www.lbbc.org>] frequently, as we are updating information on a regular basis. . . .

Let's get down to business. Our speaker today, [Ms.] Sage Bolte, will be educating us. She will offer the opportunity for questions and answers . . . at the conclusion of the program. So, hang in there and you'll get your chance to ask questions. . . .

. . . I'd like to tell you a little bit about our featured speaker, and then she will begin her presentation. [Ms.] Sage Bolte is an oncology counselor for Inova Health System's Life with Cancer program [<http://www.inova.org/healthcare-services/life-with-cancer-program/index.jsp>], where she helped develop a program that addresses the needs of people impacted by advanced or metastatic breast cancer. [Ms.] Bolte provides individual and family counseling, facilitates cancer support groups and partner support groups, and offers educational

seminars on sexuality and intimacy. [She] has presented at local, regional and national conferences on the impact of chronic illness on sexuality, intimacy, and sexual function, and how people affected by cancer and healthcare professionals can address common problems.

There are many more things that we can say to highlight [Ms.] Bolte's work . . . please welcome [Ms.] Sage Bolte.

SAGE BOLTE, ABD, LCSW, OSW-C:

Thank you, Elyse. It's great to be here. . . . I always love working with LBBC, and I'm honored to be a part of this day. . . .

I look forward to your questions. . . . If I say things that trigger a question for you and I don't answer them, write them down . . . so at the question-and-answer time, you can feel free to ask those questions. . . . If I'm not able to answer the question, I will find the information . . . and get it to you. . . . We will find a way, through LBBC, to communicate that information to you, [or we will] get my contact information to you.

As Elyse said, we're going to be talking about communicating [within], and managing, your relationships, [as well as] communicating your needs. As a woman living with or healing from breast cancer, you may have unique challenges. Many people have a limited understanding of the impact cancer and its treatments have on a woman, both in the long-term and the short-term. If you're a woman who has advanced disease, many friends or family members may struggle to understand the concept of ongoing treatments.

Since you may be dealing with some permanent changes to your lifestyle — no matter where you are in the process of treatment — it may be harder to talk about [those changes]. We'll discuss methods for communicating effectively, and get tips on finding the information and support you need to talk more comfortably with your friends, family and other support systems.



I hope that throughout this talk we'll address resources that are available to you. [I intend to address] both the effective ways of communicating about your disease and [effective ways of communicating] your needs. Hopefully I'll be able to address common themes and also look at the common themes in treatment — for women in treatment, post treatment, and women living with advanced disease.

... I think it's ... important to honor and recognize that cancer doesn't just impact the person with cancer. So although you may have the disease and are working on treatment, everyone who loves you and knows you is impacted by this disease, especially families. Family systems are a sensitive structure, and a change in one family member affects all the other members, as well as the family as a unit. Some of the [role] changes that occur ... [can add stress for all involved]. If you were the primary caretaker and now your partner is having to assume that role in addition to the other roles, stress can be experienced by both you and your partner; [as well as] ... other family members.

Sometimes — for family members and for the person with cancer — feelings of inadequacy can be experienced, or changes in parenting may occur. [Those feelings can be set off by lowered] energy levels [that occur during and after treatment], treatment demands, or [limited abilities when] returning to work. [Time can also be a challenge during treatment]: ... taking time out for your kids, ... taking time out as a couple, ... [or] taking time out just to take care of yourself. It's challenging when you're in treatment, and then when you're recovering from treatment. A lot of th[ose issues related to time-strains] can be ... [resolved]. But [the stress related to time-pressures] can be a barrier to communication, [as well as a barrier to] getting your needs met, [especially when] you're not quite sure how to ask for time together. So we're going to talk about some of those things.

Some of the barriers that have come up when I've worked with couples as well as in group settings, [include a number of behaviors]. ... You may find that your family and friends are withdrawing because of their own discomfort. I hear from a lot of women that they're always amazed to see those people who [do withdraw, sinking] ... back into the woodwork, [and they are equally surprised to see other people] come out of the woodwork during and after treatment. ... It's important to recognize that [withdrawal is]

not about you. [People typically withdraw] because of their own discomfort, whether they're not sure what to say or they're not sure how to talk about [issues surrounding cancer]. Or maybe [your situation is] striking up a fear in themselves — maybe it's too close to home. We don't know what the issues are, but oftentimes it's about them and not about you.

Sometimes there may be a barrier to communication because your partner — or your adult children, or your children, or maybe even your friends — may feel angry or resentful about this disease, and they don't know how to communicate that. ... This disease is changing their life as well, [and] they may feel angry or resentful [about] that. They may feel selfish in feeling that way, so they tend to hold it in. We're going to talk about how we might be able to address some of that.

Some people may fret over minor issues or questions about treatment. They may want to know, "What does your tumor marker say? What's the scan say? What did the doctor say? What was your red count? How are you feeling?" They may ask 100 questions the minute you return from the doctor, and you're not ready to have that dialogue yet. Because you're not ready, they may interpret that as you being evasive or not wanting to offer the information or not being informed. We'll talk about how we can help with managing some of the communication there. They may want to feel a part of your treatment, and they're just not quite sure how to do that. By asking those questions, they may feel like they're getting more control and that they're being supportive. But the outcome may be the exact opposite. You may feel like you need to distance yourself or that they're being too pushy.

You may be worried about some of the same things. Both you and your partner, or you and your friends, may be worried about the exact same things. You may be worried about treatment side-effects: how that's going to affect your ability to care for each other; how that's going to affect your ability to care for your children. Is it going to affect your work and your ability to work? Will that affect your income? Some of the late effects — what are the late effects? People may be worried that there are some long-term late effects that are going to always impact your relationship [with your partner]. Both of you may carry a fear of recurrence, [and have fear about] ... finances. [There] may be some worry about what's next. What are the next steps? What are the next steps

once you're done with treatment? Then what? What do we do? How do we put the pieces back together? Or who do we talk to? What's the care plan, etcetera? ... Because oftentimes, at least in partnerships, we may not be talking about these ... fears or concerns. We want to protect our partner from feeling uncomfortable, [and that act of protecting] actually may be a greater barrier to the communication.

I'm just going to mention some [of the] ... topics that typically get avoided, and then we'll get into more detail about how we can address those [topics]. Typically, the topics that mostly get avoided are things like ... advanced directives, [which detail one's decisions for end-of-life care; <http://www.cancer.gov/cancertopics/factsheet/support/advance-directives>]. Many times when I talk with women individually, they're very open to talking about an advanced directive. Because cancer still brings up a fear of not only recurrence but a fear of death: even though we have a great treatment for breast cancer, and we have high cure rates, and we're doing wonderful things. Sometimes, for women especially, doing an advanced directive [causes them to] feel like they have taken control and made their wishes known, in case something should happen. [It] helps them feel more in control and less anxious.

What I say to women and to their partners ... [is this]: Why not both of you do this? This provides an opportunity for both of you to take ... time to do an advanced directive, so that both of you have your wishes made known. In fact, I think all people should have something like that — whether you have cancer or not — [so that] there is communication about needs and desires.

Set some boundaries or limits [while] you're ... in [active] treatment, [detailing] ... when you'll communicate about how you're doing or what you need. A lot of people who are in a supportive relationship want to know how things are going. They may ask about the CT scan, or they may ask about your blood work, or they may ask what the doctor said or when the next treatment is. You may not be ready to talk about that yet. So it's okay for you to say, "I'm not really ready to talk about that right now. But I will let you know as soon as I get the information from the doctor," or, "Next week I'll come back and visit this information with you." If you're comfortable with that person having an open dialogue with your physician or the nurse, sign that consent form that allows [that person to] get the information on their own. ...



If you can, set some boundaries. ... Sometimes adult children want to know a lot of information because they aren't able to be ... there with you. So maybe [start a] dialogue about what they want to know. You may want to confirm ... that you will let them know when there's a treatment change: If you're starting a new chemotherapy, you'll let them know ahead of time. Same with any children at home — let them know when you get your labs back, and let them know when you'll communicate that information to them. Because oftentimes it takes a little while to get that information. So just because you went to the doctor doesn't mean you come back with that wealth of information they want to know. So, again, communicate [with] ... them so they have an idea of when to expect information. It will relieve their anxiety, and it will help you both maintain good communication.

Can you communicate that information once a month? Can you communicate it once a week? Again, you can set some boundaries about how often you're going to disclose information, and to whom. [Two] things that are helpful in disclosing that information, if you want to do it on a more regular basis, [are to] ... set a structured time, like once a week; [and create a] ... support Web site [that will communicate details of your treatment to many people at once]. I'm going to talk about [that second option] in a little bit.

And, again, having an open dialogue with whoever it is — that's your care partner, your partner, your spouse, your adult child, your children at home, your friends, your co-workers, etcetera. Communicat[ing] about the boundaries that you're setting and how comfortable you feel with disclosing the information is an important step to open communication. Offering the opportunity [for] both of you meet with a nurse ... educator who can sit down and really talk about what to expect [is important], both during treatment, after treatment [and for] long-term [care]. In those meetings you can discuss what [to] expect, so that both of you sit down and get the information you want [and get your questions answered]. Maybe a whole family can sit down [with a] nurse if you all want information, [or maybe you'll want to] ask the [family] to sit down and do an education session with you. Again, [you also have] the option of your family and friends meeting with the doctor or nurse on their own, if you're comfortable with that.

A lot of women, after we talk about some of the communication barriers, will come to me and

say, "Gosh, Sage, will they ever stop saying, 'You're still tired? Aren't you done with treatment?' or, 'What did the doctor say?'" after you went in for a simple weekly blood draw or, "When are you done with treatment again?" — and you just started. Those questions get exhausting ... [and] ... repetitive. Because ... you have [a number of] friends asking the same questions over and over again [at separate times, so] you're hearing the same questions over and over again. [That] does get old. ... So the answer to that is probably, "No, they won't ever stop asking those questions." But, again, [those questions are] really coming from a caring space. I think it's important to remember that — that when your friends are asking, "You're still tired?" they're not judging the fatigue, typically. They're just not educated about the healing time ... after treatment [or] during treatment. [In a little while], we're going to talk about how you might be able to educate them about that.

Some of the common problems that cause conflict to communication are really when your family, your partner, your friends, your employer want to problem-solve or fix the problem. This often happens in marriages, when the woman's in treatment and isn't feeling well. [She] is trying to just rest or find other solutions to feeling better; [then] her partner steps in and [tries] to fix th[e situation by] eliminating some of the issues: "Did you call the doctor?" [That "fixing" is usually coupled with] ... 100 questions to try to help problem-solve. It isn't helpful in your communication, because what that does is it sets up some conflict between the two partners. So, communicating about that [act of "fixing" when that's not what you need] ... is going to be an important step towards [open] communication. What is okay for your partner to ask, or not ask? It's okay to have a dialogue about that at that time.

[During treatment], you've had to rely more on your partner, family, or friends [to assist with] ... practical or physical things. But you still want to maintain some independence, [and that need for independence] can often cause conflict in communication, [because] ... there may be this expectation that you can't do it or they need to help you with doing it. ... They want to help you, but [being helped with things you want to do independently] can cause some conflict.

Some conflict can happen when family, partner, friend, or boss aren't educated about the immediate and long-term consequences of breast cancer and its treatments. So this can lead to

frustration for all parties. In this case, it's important to make your role as an educator, or to delegate [to] an educator. If you have a partner who's willing to be the quarterback — or the educator — of your friends and family, [take advantage of that. That person can talk to others when] ... you need four or five days after chemo to just lay in bed [and] pull the cover[s] over your head. ... Whatever your norm is, have somebody educate your co-workers and your friends and family about that so ... everybody knows the expectation[s. That information may prevent] ... frustration [and] confusion. Again, a lot of times it's just the lack of education and information that leads to conflict, [to] barriers in communication.

There's this idea of what I call "how to ask for help using the AIDR method." A-I-D-R, being an AIDR [Ask, Inform, Delegate, Reevaluate]. ... None of our employees, or friends, or family, even our partners ... read our minds: even if you've been friends since childhood, [even if] you've been married 25 years. They don't read our minds. So, although we may be feeling nauseous, or we may be feeling like we need some time alone, or maybe we want time with them — if we don't ask them for that, they're not going to know. Then we begin to resent them for not knowing. But, again, it's important that we ask for our needs to be met. So start with asking.

Then you can inform them, educate them about your treatment, your side effects, your needs, [your] recovery time. Because there is some predictability once you start a chemo treatment, if you know that on day three after chemo ... you [will be] feeling the most fatigued, you can communicate that, and you and your support system can problem-solve about the best way to support you during that time. If it's after treatment, and you're trying to find out what your new normal is, communicate that — that you're not really sure if you're going to feel good in two weeks, because you're just starting this healing process. Inform and educate. [The] same goes for your employer — inform and educate. Tell them what your needs are and inform them and educate them about what they can expect as far as your abilities as you return to work, or during [work, if you're continuing to work through your treatment]. ...

Inform them on this idea of ... the two-year healing process. Cancer really takes, in all reality, two years of your life. Then it continues to have a long-lasting impact in both positive and sometimes negative ways. But there's this two-year healing



[process] that women especially need. It's this one year of treatment, the medical part, where we are treating the cancer with surgery, radiation and chemo and other follow-up surgeries. If you have had any kind of breast augmentation or surgery: if you've had anything that needs to be followed up with . . . that [follow-up process] really takes a year. Then after that year of treatment, you're starting on that year of healing.

The year of healing is very real — it's emotional healing, it's physical healing, it's spiritual healing. You really need another year to start [returning] . . . to some of the parts of you that were [there] before cancer. I think the expectation for a lot of people — again, because of lack of education — is once you're done with treatment, you're done. That's just not the reality. The healing is just starting once you're done with treatment. You need that year of healing. So communicate and educate about that — that you don't know when you're going to feel like yourself again — that it's going to take time. Communicating . . . about your boundaries, what your needs are, etcetera, is an important part of informing.

The next part of the AIDR model is to delegate, to really assign people tasks. So you've asked for help, you've informed them of what your needs are, you've educated them . . . and then you've delegated. You've told them what they can do. You've assigned people tasks. During treatment you can assign things that would be helpful on your chemo days or weeks. During your healing time, pick a day of the week that people can help, [a time when you'd like someone to] come by or have lunch with you, or just follow-up with a phone call. A lot of times, people see a dip in their phone calls after treatment's done because, again, the assumption is, "You're done with treatment. Hooray!" [In reality that's when] you're just starting to heal, and you could really use a follow-up phone call of encouragement. So let your friends and family know that that's an important part of your healing process.

If you're living with advanced disease, make a calendar and delegate people to help. Make a calendar of when your treatments are, when you know that you're not feeling at your best, or on days that you know you need help with the kids, etcetera. [Then] delegate people to help.

And then the "R" part of the AIDR model: "reevaluate." Cancer provides us opportunities at the same time. Even though it's a hard situation, it can provide some opportunities to really

reevaluate relationships. If there are relationships in your life that are what I would describe as toxic — people who are taking more from you than you are receiving, or draining you so you feel exhausted at the end of the conversation instead of uplifted or feeling better — then maybe you need to reevaluate the importance of that relationship at this time in your life.

If they still aren't supportive after you've asked, informed and delegated, then reevaluate whether that relationship is necessary. Or reevaluate — maybe there's still a slip in communication, that maybe the way you're asking for help isn't a way that they're able to hear. . . . Maybe the way that they're showing support isn't a way that you're able to see. So open a dialogue about, "Gosh, I feel like I'm asking for help, and I've given you some information about what I need and I've delegated . . . this task [to you]. I really feel like you've dropped the ball on this." [Listen to] their response before you react, so that you can see if they've just misunderstood you.

How you can most effectively communicate about those issues is really identifying the challenges. What are the challenges you're facing in your relationship with your partner, with your children, with your adult children, with your employer? . . . Communicat[ing] effectively starts with identifying those challenges. So what are those challenges? In the process of identifying those, open a dialogue about them. Take more of a curious role, of, "You know, I've noticed that since I've stopped treatment, you haven't called as much. Do you think I don't need that continued support, or do you think I'm feeling better, or have you assumed I'm busy?" Ask with curiosity and not judgment. And that will help keep the dialogue open because, again, oftentimes it's just misinformation or misunderstandings.

When there are role changes that occur, and you're having a hard time with that change in role, you can problem-solve . . . and discuss [around those changes]. If your partner is having to take on four or five more tasks — they're having to help with the housework as well as working full time and managing the children at home — then talk about [whether you] can [ask other] people to help. [Find out if there] can be some problem-solving around that, so that although there is a shift in some of the role changes, both of you can still have time together on equal playing field. That's an important part of maintaining intimacy and communication with your partner, especially

making sure that you take time out of this caretaking role and even the playing field. [You need to find a way to] go back to being [just] partners [instead of] a person with cancer and [a] caretaker.

Learn how to relieve the tensions. Does your friend or partner need time to think about what you're asking [for]? . . . If you've noticed a problem, can you [offer] . . . that information? Maybe they need a couple of days to process [the problem], and . . . can come back to you with [details that may lead to a solution]. I know some people like to process right away and out loud. So they may see a problem, identify it, speak about it and they [immediately] talk about what they'd like to see different. If the other person doesn't respond right away, they interpret that as the person not caring or not hearing them. But it may just be the fact that they need more time to process, that they need to come back to the issue once they've thought about it. So, dialogue about that. Know what your friends [need] or your partner need[s].

Do you do your best communicating via telephone, letter, e-mail, [or] face-to-face? [Do you prefer to talk] with the information written in front of you so you can read it? Identify what's helpful to you [in order] to relieve the tension. If you know that you get anxious about any kind of confrontation or communication, find a way [to] . . . communicate your needs effectively without feeling anxious. You can write a letter and read it [aloud]. You can [use written communication as a script; reading it aloud while meeting with someone] face-to-face or [talking to that person] via telephone. Again, there are some Web sites that can also help you communicate your needs.

[Find a way to relax before going] into this communication with your friend, your partner or your employer. Take a walk beforehand, or use visualization by practicing the conversation before you have it — role-playing that conversation. I know in many circumstances, I'll role-play with the women before they go back to work on how they're going to dialogue with their employer about some of the flexibility they're going to need during [their] healing time. If you can role-play that conversation, you'll feel more prepared and more relaxed going into it. Can you have a conversation doing something active and relaxed? Can you have this conversation while you're playing a card game, while you're walking, while you're at dinner? [Combining this conversation with another activity may take some of the pressure off].



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L B B B C . O R G

I think the most important thing about communication is that you understand your own coping process and that of your family member or friend. We don't always know the coping process or the communication style of our employees or employers, our co-workers. But we do usually know the coping process and style of communication to our partners and family members. So, really, it's most important to understand your own, and then dialogue about that with your partner or your friend or your family. Remember that attitude is such a huge part of effectively communicating, too. Having a good sense of humor is a must, communicating effectively by staying calm and asking questions. And, again, try to take the approach of question-asking and [listening with] curiosity, [rather] than judgment, or expressing anger in a tone that they're not going to be able to hear.

We're now going to look at the different ways to communicate your needs effectively, both during treatment, after treatment, and then throughout living with advanced disease. For people currently in treatment ... [one] of the things that leads to [a] disconnect in communication is [a] ... lack of information about what to expect. So if you know that there's an expected response after treatment, [inform the people around you]. Do you know how you will feel, for example, three to five days after chemo? [If you know that] you [will probably] have your lowest energy [at that time], then you can tell your friends, [spouse and family] that's when you need the most help. Do you know, in advance, the next five appointments with your doctor, so that [your support group] can plan meals for you? [If they know when you'll need help, they may want a chance to plan] child care or transportation or a bouquet of fresh flowers at your home. ... The more advanced information ... you can provide, the better they'll be able to support you through that process.

What do your friends and family need to know? Technically, they really need to know nothing. However, oftentimes our partners want to be involved in our treatment, and our friends want to be involved in that treatment and the decisions that go around that. So you need to decide what ... you'll tell them, based on your relationship with them, as well as what you're comfortable with. So you may have an aunt or an adult daughter that you're very close to, that you feel comfortable disclosing more information to than you do to a friend or another family member.

That's okay. You don't have to tell everything [to everyone]. Tell [people] what you're comfortable with [sharing]. ...

I think it's also important to give yourself time to digest and understand the information first. So if you're newly diagnosed — or if you're in the middle of treatment and you don't really know what the side effects are and you haven't really experienced that yet — give yourself time first to digest and understand this information. Then communicate it to your friends and family, or have your partner communicate the information to your friends and family. Or [maybe delegate that communication to] one of your best friends.

You can give little detail or great detail, as I said before, depending on how you normally communicate, or how you decide what's best for you now. And the [depth of] information you are offering] can change. It's okay if at the beginning you want to give a lot of information, and then you decide that that was too much, people are asking too many questions, so you back off. [Your level of disclosure] can always change.

With your employers, discussing flexibility options [can include informing them] about ... what to expect. Is there any option for working from home? [If they understand something about what you'll be experiencing during treatment, they will better understand what your needs are. During that discussion, you may want to] inform them if you want to keep this a private matter. I've had many women who actually never told their co-workers that they were going through cancer treatment. The only person that knew was the HR [human resources department] and the employer — their boss. That's okay. That's your right. But you need to make sure you communicate that you want your privacy respected, and that you have the right not to tell.

You can do some of the communication by [referring] your friends, your family and your employer [to] ... [informational] Web sites. ... So if they want to know what to expect, send them to good Web sites, like the National Cancer Institute's Web site [<http://www.cancer.gov>], like LBBBC's Web site [<http://www.lbbc.org>], BreastCancer.org [<http://www.breastcancer.org>] and other reliable breast cancer resource information that can give them facts [<http://www.lbbc.org/resources-links.asp>]. ... A lot of myths are out there [on the Internet]. So send them to places [that have the best information]. Give them a list. Maybe print out a

sheet of paper that has your support Web site that will ... give them information both on your disease [and] treatment, your expected side effects and follow-up, the way that your treatment will go. That [list] will help them [stay] informed without having to ask you a lot of questions.

If you're out of treatment, it's important to remember that just because you're done with treatment doesn't mean you're done healing. You need to take that year of healing, at least. Some people take longer. Educate [others] on your "new normal." I know that [description of life after cancer diagnosis] is used a lot right now, so I just want to say that the new normal is a very real [concept] and a very real state of being. You may have to continually evaluate what your new normal is; that your new normal may be different today than it is five days from now, that today you may have a lot of energy and five days from now you may have lower energy. Educating your friends, family and employer about the fact that you may need some flexibility [while] ... trying to figure out [the parameters of that] new normal ... is going to be helpful: not only your healing process but to [your practice of] open communicat[ion].

Can you communicate to your employer that although you're done with active treatment, you'll have several follow-up appointments that will be mandatory? Ask the best way to communicate when these appointment[s] are. Would it be best to do it a week ahead, a month ahead? [Some employers want as much advance notice as possible, while others want to focus on the more immediate time-frame.] Do they want to know some of the late effects that you may be experiencing or not? Again, this is in your control. Have a doctor write a note for you about what is reasonable to be expected from you. Some oncologists are very willing to do this. If you're thinking about going back to work, can you go back part-time, [at first]? Or can you talk to the employer about some of the flexibilities [needed as you recover from treatment]?

This is where it's really important [for you] to talk to HR, [and to] know your rights [<http://www.lbbc.org/resources-links.asp#Workplace%2C+Legal+and+Insurance+Resources>]. Then think about [the following]: Can you educate the staff? Could you provide an in-service for the staff [by] a[sking a] parish nurse [or some other knowledgeable person] ... [to] come and [provide information] ... about what to expect [during and] after you're treatment? ...



Remind your friends and family that [the time] after treatment is sometimes the hardest, because the support dwindles, and there's an expectation that you're okay. But you still have a lot of healing to do. You're not being followed by the oncologist as closely as you were when you're in treatment, so sometimes that provokes more anxiety and feelings of fear. So you're going to need their support even more. . . . You're still going to need playdates for the kids. It still would be helpful to have meals brought every once in a while, or somebody stop by to help with laundry or to set up a date to talk and just connect with your friends. Remind them that it's not over — that you still need that support.

For women living with advanced disease, there's this idea of living in three-month segments: that you can plan for the future in three-month segments based [on] your scans sometimes. But . . . you can plan for the future. I think some women are afraid to plan for the future, and that can lead to a breakdown in communication. Talk about what's realistic and what's reasonable with your partner, your family, your friends — [that communication] is an important part of planning. [Keep the lines of communication] . . . open with your partner, [talk] about what's realistic. You may need to adapt your expectations and [plan] trips that allow you to rest or relax in between adventures, but you can still take a trip. If travel is what you want to do, you may just need to get travel-insurance so that you have some flexibility and you don't feel pressure, [worrying about how to manage the details, such as what you would do] . . . if you got sick or you needed to start a new treatment. [Some travel insurance policies will cover the cost of a cancelled trip, so] that you would be able [reschedule or cancel your trip] without any [financial] consequence.

Those of you who have been living with this disease for a long time [have] probably experienced this: The rollercoaster ride loses its extremes. It becomes easier to stay on, and the shock of needing more treatment or getting a bad report wears down. [As a result,] you're able to communicate more effectively about [your cancer experiences], and you have a better understanding of this disease, and the longevity of treatment. . . . If you're living with advanced disease, it's important to educate the people around you; [to let them know] that you are going to be getting treatment for a very long time. [If they are made aware of that, they may stop asking]: "Aren't you done with treatment yet?" [With the right information, they'll

know] that's not a helpful comment. I think educating them about what is helpful, and that you still need support, are important steps of open communication and continuing communication.

So, some of the tools on how to get help: . . . [For] one, you need to simplify. Spend energy on the things that really matter to you. If that means that you have somebody come over to do laundry so that you can sit and play with your kids for a half-hour, then do that. Take the help that's out there. If it means working from home one day a week instead of in the office, then ask for that support. Try to simplify as much as you can so that you really can spend energy . . . on the things that matter to you [as well as on] healing and getting better. That's [advice for] both for people in treatment, after treatment and those living with advanced disease. . . .

Allowing people to help: There are some great Web sites that I've [mentioned] to you. One is called Lotsa Helping Hands [<http://www.lbbc.lotsahelpinghands.com/caregiving/home>]. The other is called CaringBridge [<http://www.caringbridge.org>]. Both are Web sites that are free to people living with any kind of disease. It really helps in communicating information to your friends, family, people that are far away or people [who] live close. [Those resources] give you a tool to communicate information, so that you're not on the phone all the time, or so that you don't have to repeat your story 100 times.

[Planning what you want to say and writing it down or blogging it] gives you control over the information you want to disclose, over the information you feel that would be helpful. It gives you control over asking for help. So if you aren't someone who feels comfortable calling and asking for somebody to set up a play-date, this is a way to ask [all the people you know are viewing] the Web site. It sends it out to all the people that are part of your support team. So you may have 50 people on that support team, and when you ask for a playdate Tuesday, you may have ten responses. Instead of having to pick one person out, you're giving it out to your whole support system and letting them respond, which takes some of the burden off of you. So using these Web sites is a great way to keep communication open and, again, to set some boundaries.

[There are also other resources out there to help keep your household running without asking for favors from friends and family, and some offer

subscriptions that can save you money on shipping costs.] Asking and allowing for help through things like Peapod [for grocery delivery <http://www.peapod.com> is one option] . . . [and] there are other organizations like that out there [<http://www.netgrocer.com>; <http://www.spud.com>]. That's through a grocery store called Giant here in the [Pennsylvania] area where they [have online ordering and a choice of stores for pick-up <http://www.giantfoodstores.com/shareddev/sharedcontent/Ourstores/SFH>]. Again, it's a great way for friends to help. If you don't have the energy to get out and get groceries, can somebody pick them up for you? Or can they have them delivered? And the Web sites allow you to [take control of the situation, and then] ask for [help in] . . . [getting] your needs met.

Asking for a friend to come over . . . through these Web sites or through phone calls — communicating that you need joy and laughter in your life is a really critical piece. . . . We might assume that our friends know that. But they may feel like if they bring in laughter or humor that they're dismissing our experience of breast cancer. Again, it's your right to say, "I really need laughter. Once a week I need somebody to bring over a funny movie," asking for your needs to be met, again thinking of that AIDR — asking, informing, delegating and then reevaluating.

. . . You have to ask for what you want. So asking can your friend pitch in for a housecleaner once a month? Can they stop at the grocery store? Can they send you fresh flowers every couple of weeks? Can they watch the kids? Can they get you movie tickets, or a Netflix membership, or gift certificates to dinner, [or] gift certificates to some of the ready-made meal companies, like Let's Dish [<http://www.letsdish.com>]? All of those [requests] are things that you can put on your Web site, or disperse to the person who you'll delegate as your quarterback or someone who can communicate the information to your friends or family. [And those requests] will not only keep the communication lines open but will also allow for your needs to be met.

Offer your family and friends information on support groups. Encourage your partner to go to a partner support group, and your children to go to a children's support group or a young adult support group. . . . Some of that is available online, through programs like CancerCare [<http://www.cancercare.org>],



The Wellness Community [<http://www.thewellnesscommunity.org>], Gilda's Club [<http://www.gildasclub.org>]. Life with Cancer here in northern Virginia offers all of those programs. So getting them connected to resources can also help with opening communication.

I think the key ... in communication is ... looking at how can you maintain control in the situation [while also] ... letting people participate in your life. Some of the tips that you can [use to develop open] ... communication [with friends and family] are [available to help you]: The National Cancer Institute did a great job of giving ways of communication or talking to your family about your needs [<http://www.cancer.gov/cancertopics/facing-forward-when-someone-you-love-has-completed-cancer-treatment/page8>]. That starts with talking about what you think is happening with your relationships, [as well as] your thoughts and beliefs about why your relationship is the way it is. [That communication continues with you expressing] how [those relationship details] make you feel and what would please you or make you feel better. So [the process is as follows]: you give a fact, then your belief, and then your feeling about that, and then what you would like to see different.

I think we typically do really well about stating a fact and our belief and usually how it makes us feel. We're really good at that. But we're not as good about saying, "Here's what you can do about it so that we can work together to make this better." You may want to say to your friend, "Ever since my last scan, you've called me less," or more, whatever the truth statement is. That's a fact. Or, if you're the partner listening in on the phone call, you may want to talk about intimacy with your loved one. You might say, "It seems like because our sex life has changed. We aren't spending as much time being intimate or close." Again, that's a fact.

The second part of this communication would then be stating your belief, why you think that is there. If you're communicating to your friend about not calling as much, you may say, "I think it's because you're uncomfortable with the news that this is going to be going on for a while, or you're uncomfortable with asking me about cancer, or you believe that everything in my life is normal," which is typically the case after you've completed treatment. So that is your belief — why you think they're reacting the way they are. In the case of the partner, if you're talking about

sexuality and intimacy, you may state, "I think it may be because you aren't sure what I can do or you assume that I don't want to be touched like I used to," or that you[r partner doesn't] want to be touched.

Then you state your feeling, how [that fact you just stated] makes you feel. So you're communicating a fact, then a belief and then your feelings. For your friend, you may say, "I understand you care. But when you decrease your calls, it feels like you are not as concerned about me anymore." Or, for the friend that calls you a lot, you could say, "When you increase your calls, it feels like you don't trust me, that I'm not communicating the information to you, or that you're hovering over me. It makes me want to communicate less with you. I feel like I need to protect you from the information." I hear this a lot from families with their adult children. Or, if they don't call, as I said before, "When you don't call, I feel lonely and confused, and although I'm happy about being done with treatment, I still need support in my life. I want to hear about your life, too."

For the partner, when you're talking about your feelings in this example around sexuality and intimacy, you may say, "When we don't touch or spend intimate moments together, I feel lonely. I miss being close to you. Sometimes I also feel angry that cancer affects our intimate life, too."

Then the last part of this — and this is almost the most important part — is your needs, what you need done next. So, for the example, with the friend, say, "It would be great if we could schedule some regular time together where the focus wouldn't be on cancer. I promise I'll bring up what needs to be said." Then, for the partner, "I'd feel much better if we were more intentional about our intimate time — and that could or could not include sex — but, again, if we were more intentional about our time."

So, again, you're stating a fact, your belief, your feeling and then your needs on what can be said. As you're listening to the person reflecting back to you, ask questions and show interest. Make sure that you're actually listening to what they say and not building the rebuttal in your head, that you're actually communicating [by stating facts and feelings and then listening to the answers you receive].

Finally, for the last couple of minutes, I just want to talk about communication with children, both adult children and [young] children. The

most important thing about communicating with kids is children have very imaginative minds. If we are not honest with them, they can develop very scary stories in their heads. Now, you know your children best, and you know where they are developmentally. But the counselors at your child's school — or if you live near a program like Life with Cancer and have counselors here that specialize in children and their needs — [counselors may have expert-advice on] what would be developmentally appropriate.

But one thing we really recommend is not to hide cancer from your kids. It's really important that you're honest with them. Give them the opportunity to ask questions. Sometimes all they need is the basics — when you have a scan, what the treatment is, what works, when you're feeling tired and why. It might be helpful for them to talk to a nurse, and the nurse can do some education with them at their level.

Keep life as normal as possible for them. Keep them engaged in school. Have your friends help with playdates. Life isn't going to be "normal" — [it won't be the way it was] ... before cancer — but to try to keep it as consistent and predictable as possible. [That consistency] is the best environment we can provide for kids during cancer treatments.

Find ways to connect with them in their own way and help them feel part of the process, as much as they want to be. ... If you don't have the energy to play soccer with them, can you sit down and read a book? Can you sit down and play a board game? Can you get on the computer with them? Can you dialogue with them at dinner? If [you know you are always] tired at night, can you have a little bit longer of a breakfast? Get creative in how you communicate.

For those of you living with advanced disease, don't wait to see how you feel to tell them you've switched treatments. A lot of women will say, "Well, I want to see how this new chemo makes me feel before I tell my kids." Oftentimes the kids feel betrayed that their parent didn't tell them [about a new treatment]. Especially if the [ir parent has] a big reaction, and goes to the hospital or [isn't] feeling [well] the next day. [Children get] confused [about] that. So just keep them informed in developmentally appropriate ways.

If you have adult children, give them the opportunity to participate in the way that they want to participate. Don't try to protect them from information. Offer them the information.



Let them come to you with what they want to do and how they want to be involved. Ask what they want and how they want to be involved. Provide them the opportunity to talk to the doctor, or the nurse, or to come with you to treatment — if that's helpful.

All of these things are important in maintaining communication with your kids. Again, the biggest thing is just being honest and not leaving anything to their imagination.

As we wrap up, remember that when you know what your fears are — loss of income, loss of a dependable spouse, fear of death, fear of ongoing treatments — if you know those fears, you're less likely to express them inappropriately or take them out on others. If you're aware of [your fears], you'll be able to communicate about them more effectively.

Remember that you have control over who you choose to communicate with and how you choose to communicate. So, identify your own needs. Recognize that you have some control over that. Learn to use "I" messages. So, "I feel angry when we can't go on our favorite vacation because of my treatment." Or, "I feel great that I'm able to pick up the kids from school today." Offer your "I" statements — it avoids blame and it keeps the lines of communication open.

When you're communicating — whether it's with your partner, your family, your children, your friends or your employer — remember to take into consideration that you need to keep those lines of communication open. Take a curious approach [and ask] questions. Ask how much information [people] want to know. Give them a resource list of information. ... Use [a personalized] Web site to help communicate information. Again, remember that you can take as much control as you want over the amount of communication or information you provide. [Although] your partner may want [additional] information.

... That's the one thing I also want to point out, is you may find that your partner or your children want more information than you want [regarding your condition]. That's okay. They have the right to want that information, but what you need to communicate about is: Can that person get the information from your doctor or nurse, and be able to respectfully honor the fact that you don't want that information? If they aren't capable of doing that, then you need to dialogue about that.

If you find that your communication with anyone continues to hit walls, that you're just not getting anywhere, seek out some support [from a counselor, friend, parishioner or counselor]. ... If you continue to hit barriers, you probably want to seek out some [professional-level] counseling and support services. There are a lot of resources out there now that can be helpful. I'd encourage you to keep those lines of communication open no matter how challenging they seem. Communication really is an important part of healing.

So, thank you for your time. I want to open it up now to questions.

ELYSE S. CAPLAN, MA:

Thank you so much, Sage. In a little less than an hour, you covered a very vast array of information on communication, which I think all of us know ... is key to your quality of life — to getting your needs met, your desires met. Typically I would re-tap some of the highlights, but there were so many. It seemed like everything that you shared with our audience today, every single item was really important: the boundaries and limits, the being aware of your fears, the common problems that may result in conflict, a really big theme on being an educator and helping to inform people. Certainly at Living Beyond Breast Cancer, education is the key, and it underscores everything that we do here. I think your framing [of the] discussion [is very valuable]: about how important it is for people with cancer to really educate those around us, about things that are important to us, or things that are helpful or not so helpful.

I particularly liked how you split out [the communication process]: to present the facts, and then your beliefs, and then your feelings and your needs. I think if we can look at things in that way, it could be really helpful in or communication strategies. [You also touched on] the importance of really being honest with ourselves and with others so that nothing is left to [the] imagination. I really think [when too much is left to the imagination it] can get in the way of effective communication, just because a lot of people have their minds going in a million different directions. They may be real or they may be perceived. But we do have control over who we talk to and how we talk to them. You offered some wonderful strategies.

With that, before I turn it over to the [audience for] questions, I wondered if you had anything

specific to offer ... that may be [specific to] women who partner with women: [mainly] as it relates to physical or emotional well-being and the communication that might take place between two women [in a committed, love-relationship].

SAGE BOLTE, ABD, LCSW, OSW-C:

I don't think there's any difference between heterosexual and homosexual couples in communication style[s]. ... My experience in working with women who partner with women, there is this expectation that, "Because I partner with a woman, she'll understand my needs." That's just not the case. Just like anyone else, [a partner doesn't] necessarily understand [what hasn't yet been communicated to them]. [She] can't read your mind. So it's just as important that you communicate your needs and your feelings to [a] partner. ...

As far as body image, the issues are the same whether you're in a heterosexual or [in a] same-sex relationship. Communicating about how you're feeling about your body, how you're feeling about the changes in your body — it's really important to [have] that communication. A lot of times, partners are extremely afraid to initiate any kind of intimate touch, because they're afraid of hurting the woman with cancer, or they're afraid that they may come off as looking selfish. So they withdraw. Then the woman with cancer interprets [that] withdrawal as, "She must not want me anymore," or, "He must not want me anymore. I must not be attractive" That's typically not the case. Usually it's ... fear that [has caused] the partner [to] withdraw.

But if you are in a female relationship, I think the issues are the same. Communication is absolutely essential. [It is important to remember that] your partner [cannot] read your mind. Keep [the lines of] communication open about all of that — about body image, about some of the struggles you're having, about self-identity with either breast-loss or changes.

ELYSE S. CAPLAN, MA:

I appreciate you addressing that, Sage. With that, I would like Raquel, our operator, to come back on the line and remind everyone how to get into the question queue.

OPERATOR:

At this time, I would like to remind everyone, in order to ask a question, press star, then the number one on your telephone keypad. We'll pause for just a moment to compile the Q-and-A roster.



LIVING BEYOND BREAST CANCER®

L B B C . O R G

... Your first question comes from Westville, New Jersey.

SAGE BOLTE, ABD, LCSW, OSW-C:

Hi.

CALLER:

I'm calling — you talked a lot about dealing with partners, dealing with adult children, dealing with children. I'm 41 years old, and this is my second cancer diagnosis. I'm stage IV now. My biggest challenge is actually in dealing with my mother. ... Because she's my mother she's gone into über-mother mode. Trying to set up boundaries doesn't work really well, because she's the mom.

SAGE BOLTE, ABD, LCSW, OSW-C:

I hear — actually, you're not alone in that. Thank you for pointing that out. There are a lot of women out there who are struggling with their relationships with their parents, as the adult child with cancer struggling with a parent who wants to hover, and take care and fix. A lot of times, their hovering and wanting to fix and all of that is really about their own anxiety, their own guilt, their feelings of fear. I hear from a lot of parents of adult women with cancer: "This just isn't how it's supposed to be. My daughter's not supposed to have cancer. She's not the one who's supposed to be sick. It's supposed to be me. It's out of sequence. It doesn't make sense." Their reaction to the woman with cancer is so strong because it's displaced around their anxiety and fear and feelings of guilt.

But the boundaries can work. I've seen them work here, just in [my interactions] with families. I would suggest going and seeing a counselor with your mom ...

CALLER:

Yes. I understand what's driving it.

SAGE BOLTE, ABD, LCSW, OSW-C:

Sure.

CALLER:

I get it. It still makes me crazy.

SAGE BOLTE, ABD, LCSW, OSW-C:

Yeah, absolutely. Absolutely.
[Speaking simultaneously]

CALLER:

— that I've been trying to — you know, I've tried to set boundaries. I've tried to do it in a kind and gentle way. I've tried to be — to reinforce that. I've suggested counseling. I'm just not getting anywhere.

SAGE BOLTE, ABD, LCSW, OSW-C:

... I understand the frustration. When you're trying all those things and [they're] not working, and looking for that other magic wand. I don't know that I have it [to offer. But] ... you [do] have the option to say, "Mom, I'm going to stop offering you information at all if you continue to push this way." If you've tried doing that very kindly, and she still can't hear it, you may need to get more direct. Or, take her into treatment with you and have the nurse or the social worker there on site, someone to help be that buffer.

I'm happy to talk to you offline about that, if it would be helpful. ... I think when we're dealing with a parent, it is harder to set boundaries because they're our parent. But we still — you're an adult woman, and so you still have some power around what you choose to disclose and not disclose.

You also have power over answering phone calls or not answering phone calls, or setting time aside, saying, "On Wednesdays, we can talk about cancer. The rest of the week, if you try to bring it up, I'm not going to talk about it." Be consistent with that and look at other ways to set boundaries that feel comfortable for you, still being empathetic to ... where her anxiety is coming from. ...

But I'm happy to talk to you off this call at any point.

CALLER:

Okay, great, thank you.

SAGE BOLTE, ABD, LCSW, OSW-C:

Yeah.

OPERATOR:

Thank you. Your next question comes from Seattle, Washington.

CALLER:

Hello. I had a question about — you talked about dealing with your employer. What about people looking for a job? How much should they communicate to their employer about what they're going to need in the future?

SAGE BOLTE, ABD, LCSW, OSW-C:

That's a great question. There's not really a blanket answer to that. Legally, there are a lot of things that protect you. ... If you are completed with treatment, you are not obligated to report that you had cancer. If you are currently in treatment, you do need to report it to Human Resources because ... they need to know the flexibility and requirements you're going to need. [But you don't] have to report it [to Human

Resources] until after you've been offered the job.

Typically when we're dialoguing about that, I'd ask some questions about [the role you're interviewing for]: ... what's the [workplace culture in regards to sick-leave, pace of work and schedule-flexibility, and] ... what are the demands [of the position regarding hours per day and per week, availability in off-hours and workload]? Are these demands that you think you can reasonably meet? If they aren't, is this really a job you want to be in? If it is [a job you want to be in], then dialoguing with Human Resources about what you may experience over the next year or two with follow-up appointments [is a good idea]. ...

Typically, it's not recommended that you disclose that in your first interview. Wait until they've seen you, they know your capabilities, you're in and maybe offered the job. Then you can go and dialogue with them about some of the flexibility you may need. Give them very sound information, [as an example, you might say]: "I know that every few months I need to go in for a scan," or, "Once every six months I need to follow-up with my oncologist." Or, you know, "I need monthly Herceptin treatments," or whatever that may be, and then say, "This will not interfere with ... my job performance, but I will need some flexibility with appointments." The more you can reassure them of that [the better. However] ... you are protected legally, so as far as disclosure and not being able to be hired because of cancer. ... That's illegal.

CALLER:

Okay. Yeah, I'm considering doing — I'm trying to look for a job, but I'm also planning on doing reconstruction. It's sort of hard to go in and say, "Hey, thank you for hiring me."

SAGE BOLTE, ABD, LCSW, OSW-C:

"By the way, I have to go out and get new boobs."

[Laughter] [Speaking simultaneously]

CALLER:

— new boobs.

SAGE BOLTE, ABD, LCSW, OSW-C:

Right. So, I think you, again, once you've interviewed and you're engaged in [that new role], you might want to consider waiting a little bit longer for the reconstruction so that you can get in the flow of the job. Some of that is just thinking about what's the cost-benefit to the employer. They do have a business to run, so they have every right



to kind of challenge that. But I would go back after . . . you've been offered the job, say, "You know, I have some follow-up surgery that's very procedural. It's well tolerated. I don't expect to be out more than," however long, a week or two. "But it's in finishing up my breast cancer treatment." I have yet to experience someone who has disclosed that after they've been offered the job and then people say, "Oh, I'm sorry. That won't work." So use your better judgment.

CALLER:

Okay, thank you.

OPERATOR:

Your next question comes from Lancaster, New York.

SAGE BOLTE, ABD, LCSW, OSW-C:

Hi.

CALLER:

Hi. I was just wondering — I feel kind of a frustration because there's not a lot said about stage IV people. I'm trying hard to deal with that.

SAGE BOLTE, ABD, LCSW, OSW-C:

From what aspect? On communicating about what living with advanced disease is like?

CALLER:

Yeah, I guess, because — well, first of all, because a lot of people don't even realize that you're living with something that —

SAGE BOLTE, ABD, LCSW, OSW-C:

Right, is chronic.

CALLER:

Yes, yes.

SAGE BOLTE, ABD, LCSW, OSW-C:

Right.

CALLER:

I don't know. It's just — I just feel — I feel like my relationship with my husband has suffered. And, you know, it's just — I don't know. At times it's all-consuming.

SAGE BOLTE, ABD, LCSW, OSW-C:

Sure. You're not alone in that. I'm sure there are a lot of women on the phone that feel that as well. When — as I talked about before, if you're living with advanced disease, really communicating that your new normal may change on a frequent basis. Unfortunately there isn't as much predictability with that — everybody's going to need to be flexible with that. I think the hardest part about women living with advanced disease is oftentimes you look,

"healthy." You look good. You don't look like you're not feeling well. You don't look like you have a chronic illness that's visible to them. Even if you don't have hair, a lot of people will say, "Gosh, I had no idea." Unfortunately, again, that comes from ignorance . . . and not intention . . . that they're responding that way.

. . . I think that although it is really important [for you] to provide them [with] education, I really understand [your frustration]. I heard this when I spoke at the conference for LBBC, women saying, "I don't want to be the educator. I feel like I have to do so much else. I don't want to have to also be my own advocate and the educator." I can empathize and sympathize with that. But the reality is, if you want to see change, you're going to have to take on part of that role.

So, part of your role is really educating people that, "I have advanced disease. I'm never going to not be on treatment. The reality of my life is that treatment may switch on a frequent basis, and it may not. We can treat this well, and we can treat it for a long time, but I am going to forever be on treatment. That includes scans. That includes chemotherapy. That includes radiation. When something changes, I'll let you know. But you can just expect that I'll be on treatment. So the next time you ask me, 'Are you done with treatment yet?' I'm going to give you the same response — 'no.'"

CALLER:

Right.

SAGE BOLTE, ABD, LCSW, OSW-C:

"I'm going to be on treatment for the rest of my life." Sometimes even using humor with it is good. There are a couple of women I've met along my journey here that keep little cue cards of who they are and a summary of their Web site — like their Lotsa Helping Hands [<http://www.lotsahelpinghands.com>] Web site or their CaringBridge [<http://www.caringbridge.org>] Web site — with a little summary: "I have metastatic breast cancer, and here's what that means for me. It means that I'm going to always be on treatment. It means that I'm going to be visiting the doctor at least once a week — if I'm lucky, maybe once every three weeks. I will constantly be on some type of an infusion treatment or hormone treatment or radiation or more surgery." They do a little summary, and they have those printed out. They will just hand it to the people who keep asking the same questions. And they leave it at that.

The other option is using the Web sites to filter that information and continue to inform people that this is the reality, that living with this disease is your new reality. Although it may not be visible to them, you are constantly living with it, and although you may look, "good," that you may still be struggling with fatigue. The best way to keep people informed and educated is using Web sites, or just being assertive [and] saying, "I'm not feeling good today. I know that that can get old to you. And to me it gets old [too]."

I think that's the other piece, is your partner is probably just as frustrated as you are about the days you don't feel good. . . . It's hard. I hear from — especially from men who've partnered with women — that it's exhausting. It's an exhausting ride, that they're constantly feeling in-the-balance. So appreciating that on both ends, but setting a time aside to enjoy each other and not do the "cancer world" for a couple of hours each week. Just to kind of separate cancer and get back to who you are as a couple is a really important part. And, again —

CALLER:

I think that's the hardest thing is to try to separate the cancer —

SAGE BOLTE, ABD, LCSW, OSW-C:

[Yes].

CALLER:

— because it just seems like it's everywhere.

SAGE BOLTE, ABD, LCSW, OSW-C:

All-consuming, [yes]. As time goes on, sometimes that gets easier. But I think some of that is just being intentional. Seeing a counselor with some of the cancer organizations can be really helpful in . . . figur[ing] out, "How do I find balance in the midst of living with this disease? What are the things I need to do to feel free from this burden, so I can actually go on with living in spite of having this disease?" There are some great resources out there. There are also some online metastatic breast cancer support programs that might be —

CALLER:

I've been doing that quite a bit.

SAGE BOLTE, ABD, LCSW, OSW-C:

Great, great. So keep throwing that out to that group. If I can dialogue with you offline and give you some more personal information in regard to your specific situation, I'm happy to do that.



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CALLER:

Okay, that's great. Thank you so much.

ELYSE S. CAPLAN, MA:

Thanks. I'd just like to remind those women on today's call who may have advanced or metastatic breast cancer, if you're not familiar with the newer Web site [for Advanced Breast Cancer Community, <http://advancedbreastcancercommunity.org>] that is a great forum in which to dialogue on discussion boards.

SAGE BOLTE, ABD, LCSW, OSW-C:

Absolutely.

ELYSE S. CAPLAN, MA:

You can connect with other women in a similar circumstance.

I have one request: Raquel, if you could let people know once again how to get into the question queue. While she's making that announcement, Sage, I'd like you to be able to talk for a moment about the long-term survivor who may be on our call. [These are] women who are five or more years beyond their diagnosis and treatment . . . who may still be struggling with communication issues. [These issues may trace back to a lack of communication early in their illness], either because it was too hard [to discuss it] years ago, or [because] there are some lingering issues that still remain; [or issues] that may be unique to someone who's been living with this diagnosis for many years.

So, while you're thinking about that, let's let Raquel give the instructions to get into the queue.

OPERATOR:

Again, as a reminder, in order to ask a question, please press star one on your telephone keypad.

SAGE BOLTE, ABD, LCSW, OSW-C:

Well, for the women on the phone that are five or more years out from being diagnosed and treated, and you are considered in that survivorship category of this disease, I think, as Elyse said, sometimes we don't deal with it at the forefront of the diagnosis. At the tail end, or maybe years later, issues start to come up that we either suppressed, or we didn't have time to deal with, or emotionally we weren't aware of them. Now they're coming up for us. Or you're starting to date and you're wondering, "How do I disclose about my history?" All of that, those are great questions.

I want to first just offer you permission, that there is no right or wrong way to do this, that it's

okay to realize five years down the line that you're struggling with the fact that you were diagnosed with cancer, and you didn't think you were [struggling] four years ago. It's okay. There's no timeline for when you should be "over it." I hear that a lot from women, that they hear from their friends, "Aren't you over that yet?" Again, this is a lifelong, impacting diagnosis. So, give yourself permission to be okay with being unsure about how you're doing with this. . . .

Talking to a therapist about it, [or] finding an oncology social worker who can do counseling with you around the survivorship issues [can be very effective]. . . . Talking on survivorship Web sites is a great resource. Going to a breast cancer support group and dialoguing about some of that can also be very helpful, even if you're in the midst of women who are currently in [active] treatment.

Some of the things that you can begin thinking about, again, are: How did this impact me and how can I communicate that? So if you're wondering about dating, for example, and you're not sure how to disclose your story, or if you have a new friendship, cancer is part of your life story. It doesn't define you, but it's part of your life story. When and how you disclose it — think about that. I guess think about it from the other person's perspective. When would you feel comfortable finding that out? If you were going out on a date with someone, and they were going to disclose to you that you were a survivor, when would you want to know that? Would you want to know that on date one, date two, date three? Then decide for yourself what you're most comfortable with.

When it comes to dating, the best advice I got from a friend of mine who's a survivor is: She decides before date four to disclose that she's a survivor, because she knows herself well enough to know that if she goes on date four, she's going to want date five. Then she's begun to get emotionally invested in the person. So telling people before you get [too] emotionally invested [is preferable]. . . . They're going to ask questions, [such as], "What does that mean?" One woman came and said, "Somebody asked me 'am I in the clear.'" Be able to respond to those kinds of questions. Open a dialogue about it. Sometimes practicing or role-playing with a friend about how you might disclose that is important. Remember that this is just a part of your story, it doesn't define you. . . .

But, again, I think the most important thing to remember is that there is no right or wrong way to heal and deal with breast cancer. You can be ten

years out and suddenly realize, "Oh, gosh, I never really appreciated how much the loss of a breast impacted me, and I'm really feeling sad about that." Find some support, whether it's talking to a counselor, talking to a friend, talking to a parishioner — whoever you're comfortable talking with — to open the dialogue about that.

I don't know if that answered your question, Elyse. But those are some thoughts that come to mind.

ELYSE S. CAPLAN, MA:

No, I think that was really helpful. And with that, I'd like to turn it back to Raquel.

OPERATOR:

Your next question comes from Millstone Township, New Jersey.

CALLER:

Hi. My question is — let's see. You mentioned about the partner who's in your face constantly, "What can I do," trying to fix things. But what do you do when you have family — and it could be my husband and children — who are kind of oblivious to what's going on?

SAGE BOLTE, ABD, LCSW, OSW-C:

Hmm.

CALLER:

I was diagnosed — my third time was this year, metastatic. I reached out to LBBC and other organizations and got these great people — I think this might be part of it, all these great stories about people with metastatic disease who are doing great. It's like, to me, I feel like the world's just gone upside down. [But to] my husband, nothing has changed. A good example would be like trying to change everyday eating habits in the house, and I don't get the support from my husband that I'd like.

SAGE BOLTE, ABD, LCSW, OSW-C:

Hmm. You have a great example. I think a lot of women can also relate to what you're saying. My guess is that their way of coping is by responding in the way that nothing else is different, because for them to change things would mean life has changed. Sometimes that's just too darned scary for people, to acknowledge that the rock of the family — or the mom or the wife or the friend — is sick. Yet she doesn't look sick. She doesn't act sick. It goes back to people not being able to really make sense of [it all] — especially [for] women living with advanced disease. Because we do so well at treating advanced disease that we can really give women high quality of life, [to the



extent] that people can't really appreciate that internal struggle that a woman goes through.

For the example of changing diets: I might go back to your husband with the dialogue I gave you before — the fact, belief, feeling — and then state what needs to change, and use that as an example. So you might go to him and say, stating a fact, "You know, since I was diagnosed with this, I'm sensing more anxiety. There are some things I really would like to change about my lifestyle and our eating habits, because I believe that they will influence not only my quality of life but my longevity. . . . It's important to me that you support me in this process. You can do that by helping with changing the lifestyle or the eating habits in this home, not just supporting me and my eating habits. [I want to] . . . make this a family thing, because that [would] show me you're supporting me and my needs and my desires, and that you support me in communicating that to the kids."

So, I'd take some approach — a very direct approach. Be very specific on what he can help you with. Tell him why it's important to you, that you believe this will help with improving your length of life, . . . [and] your quality of life. If he reacts by saying, "Well, that's silly. How's food going to help?" say, "It doesn't matter if it's silly. I'm asking you to support me." I think the more direct you can be [the better] — as crass as that may sound. Discounting that [resistance is fair at this point] — you're not discounting that he's feeling confused. I think you go back and say, "It may not make sense to you, but it's really important to me. So important to me that I'm asking you and the family to support me in this."

That goes for other things as well. If you're fatigued and they don't really understand that . . . [it may be because] you've bounced back before you're just going to bounce back [again]. Their expectation[s] need to change. That goes back [to] communicating — giving them examples. If they can't react or change, then it may be that you are going to have to make changes for yourself. If they don't follow suit, then that's their choice. Continuing to get frustrated about it is only going to hurt you. So you may need to reevaluate. "If they're not going to choose to follow suit, [if] they're not going to support me in this, then I need to go ahead and do it. Because I know it's right for me. They can make their own choices, because they have the right to make their own choices, but I'm going to make a choice in my [eating] habits. . . . If they don't want to eat what I make, they don't want

to eat what I make. If they want to go to the grocery store and buy their own food because they don't like what I'm making, then they can go to the grocery store and buy their own food." But set some boundaries in that.

Over time people will adjust. But I think a lot of it stems from family members not wanting to accept that this is a life change, because it's so hard to swallow.

[Speaking simultaneously]

CALLER:
I feel like he's — my husband in particular — is afraid and doesn't want to accept what's going on.

SAGE BOLTE, ABD, LCSW, OSW-C:
That's right.

CALLER:
My kids, as soon as they heard that I wasn't going to go through, "full-blown chemo" and losing my hair, you could see the relief on their faces. That, "Oh, this is not so bad."

SAGE BOLTE, ABD, LCSW, OSW-C:
Right. "This isn't a big deal."

CALLER:
Not a big deal.

SAGE BOLTE, ABD, LCSW, OSW-C:
Right. And that's unfortunate. It's great that you don't have to go through the big guns, as I call them. But it's unfortunate that they interpret that as, "It's not a big deal." So you [need to] provide them with information and education . . . about the chronic [nature of this disease] . . . and the "unknowns" and the ambiguity that you have to sit with every day. Because, in their minds, if you're doing all the normal things you were doing before, then you're doing fine. So being open and honest about some of the internal struggles [you endure] and some of the lifestyle changes you want to make . . . is important.

CALLER:
I've never had so many compliments on how great I look [laughter] when I went through breast cancer the second time around. That's kind of ironic.

SAGE BOLTE, ABD, LCSW, OSW-C:
Yeah, yeah.

CALLER:
Okay.

SAGE BOLTE, ABD, LCSW, OSW-C:
Okay?

CALLER:
All right. Thank you.

SAGE BOLTE, ABD, LCSW, OSW-C:
Thanks.

OPERATOR:
You're next question comes from Ottertail, Minnesota.

SAGE BOLTE, ABD, LCSW, OSW-C:
Hi.

CALLER:
Hi. I'm six or seven years out from treatment, but still do MRIs and blood work and all of that. . . . I feel that I've lost my family. Even as I decorate the house, I'm saying, "But this is better than a toxic, overbearing, critical, judgmental relationship." But [I] miss the closeness.

SAGE BOLTE, ABD, LCSW, OSW-C:
Absolutely. Absolutely.

CALLER:
So can you speak to that struggle of, "Yes, [I] think [I'm] doing the right thing," but —

SAGE BOLTE, ABD, LCSW, OSW-C:
But it's a lonely process.

CALLER:
Yes.

SAGE BOLTE, ABD, LCSW, OSW-C:
Absolutely. . . . I really can understand and hear the sadness in you, just the loneliness, especially with the holidays here. I just want to honor that.

But I think the best thing you can do for yourself is to continue to recognize that what you're doing for yourself is a very positive and healing choice, even though it comes with some pain. . . . Look for a support system outside of your family, [such as a] church group, a support group, [or some other] . . . pseudo-family that you've created. . . . Seek support outside of your family, so that you can still have a family unit, especially during the holidays. . . . Again, some of that may just be continuing to recognize that although you're making a choice that's right for you, it doesn't mean that it's easy: . . . Honor that, that not only [do you] . . . have an amazing amount of strength and insight to know that you need to take care of yourself, but that it's going to be hard.



[It may help to] . . . dialogue with a best friend about that, or . . . write a letter to your family. You don't ever have to mail it, but sometimes just writing that down can be very therapeutic and healing. Writing down the sadness or the things you miss, or even reflecting on the things that you miss, the very positive things, or the holiday memories that you have that are warming to you — that are good memories. Write those down and either mail it in a letter or just keep it for yourself, just as a therapeutic tool.

I think the most important thing — especially during the holidays — is that you reach out to other support systems. . . . If you are alone at the holidays, find a friend that either you can go visit with or join in [their celebration]. People are very open to others inviting themselves . . . during the holidays. So if you have a friend and you don't want to be alone during the holiday, inviting yourself to participate at some point with their holiday festivities, maybe that might be an option.

I think you'll find that if you go onto some of the online groups, there are a lot of women who are really struggling with this same issue. I applaud you for having a good sense of yourself and knowing what you need to [do to] take care of yourself and continuing to do that despite the struggle.

CALLER:

I have a follow-up, I guess. My husband is supportive of — you know, cutting off those relationships. So that's just a piece of the ongoing care of yourself, right?

SAGE BOLTE, ABD, LCSW, OSW-C:

Mm-hmm.

CALLER:

Because — can you speak something about risk fact[ors in communication] for those of us who've come through cancer treatments, no matter what stage we are? I guess in my heart I've recognized when people don't respect you. I mean literally respect you.

[Speaking simultaneously]

CALLER:

. . . That last woman was saying, at some point, husband and children — whatever.

ELYSE S. CAPLAN, MA:

It sounds to me like you'd like Sage to address how you can communicate with those that may be speaking to you in a way that doesn't feel respectful — how you can communicate effectively.

CALLER:

Well, when you realize that the respect's not there, and you finally just stop communicating, because there's no hope for change.

SAGE BOLTE, ABD, LCSW, OSW-C:

That's a choice that some people have to make, and it's unfortunate. I hope that before those decisions are made, counseling has been tried — at least individual counseling — to find the best communication styles. Family counseling [may also be an option].

But there are situations — and it saddens me to even acknowledge that — but there are situations and times where relationships are severed because they are so toxic that they are physically and emotionally unhealthy for you. Usually that stems from, like you were saying, the fact that they aren't respecting you. Maybe you're feeling like they didn't respect your life, your livelihood. That's a hard space to be in.

CALLER:

But the cancer does force that.

SAGE BOLTE, ABD, LCSW, OSW-C:

To reevaluate that, absolutely.

CALLER:

Yes.

SAGE BOLTE, ABD, LCSW, OSW-C:

Absolutely. Absolutely, yes.

CALLER:

Thank you.

SAGE BOLTE, ABD, LCSW, OSW-C:

Mm-hmm.

ELYSE S. CAPLAN, MA:

Thank you. And take good care.

And at this point, I'd like to just ask Sage: Do you have any closing comment to make?

SAGE BOLTE, ABD, LCSW, OSW-C:

I think as we've heard everybody's stories, [I just want to remind everyone] how important communication is, and [encourage people to] really take the lead on educating people around you about what your needs are: not just about the treatments, and not just about the cancer diagnosis, but really educating about what your needs are. What they can expect, and that [those expectations] may change. So everybody, unfortunately, is going to need to live in a mild state of ambiguity, that there's some unknown out there. That's frustrating for people, especially in this society. We like to know. We like to know now. We like to get it. We like to get it now.

So just recognizing and honoring the fact that we may need to sit in a little bit of . . . ambiguity, and . . . communicate needs and . . . boundaries is a really important part of continuing to heal.

ELYSE S. CAPLAN, MA:

I think that is a really good statement to make to sort of close out the program.

I want to encourage all the people on today's call that Living Beyond Breast Cancer has message boards available [<http://www.lbcc.org/forum/default.asp>]. This may be a really good place for you to post some of your thoughts and concerns. You may find a lot of support from other women who may be dealing with similar communication difficulties or other aspects of their breast cancer. I encourage people on today's call that, if it's helpful to you, visit <http://www.lbcc.org>, [and] continue the dialogue we started on today's call. Perhaps you'll find others that may have additional tips that have worked for them.

I'd like to thank everyone for taking time, and especially the women who were able to ask their questions, for your honesty, your candor, your openness. It is your ability to put yourself out there that helps us at LBCC develop programs that can more fully serve you. So we really appreciate your sharing of your experience with us and allowing us, in some way, to try to assist you in your ongoing recovery from breast cancer.

I also want to remind folks that we do have an MP3 recording . . . So if you'd like to listen to this again, please feel free to do so. For anyone who is looking for peer emotional support from a woman who's been treated for breast cancer — a breast cancer survivor — from early stages to advanced stages, we do have our toll-free Survivors' Helpline. That number is (888) 753-5222. You can connect with another woman who's gone through breast cancer treatment. [Her perspective] may be helpful if you want an objective, outside person who can understand some of your concerns.

With that, I'd like to thank Raquel for doing a great job on today's program. I hope you stay tuned for our next program, as I mentioned, the next teleconference, which is January 26. And with that, I hope you all have a good rest of your day, and wishing you good health in the coming year. Thank you.

OPERATOR:

Thank you. This concludes today's Living Beyond Breast Cancer conference call. You may now disconnect.

[END OF TRANSCRIPT]